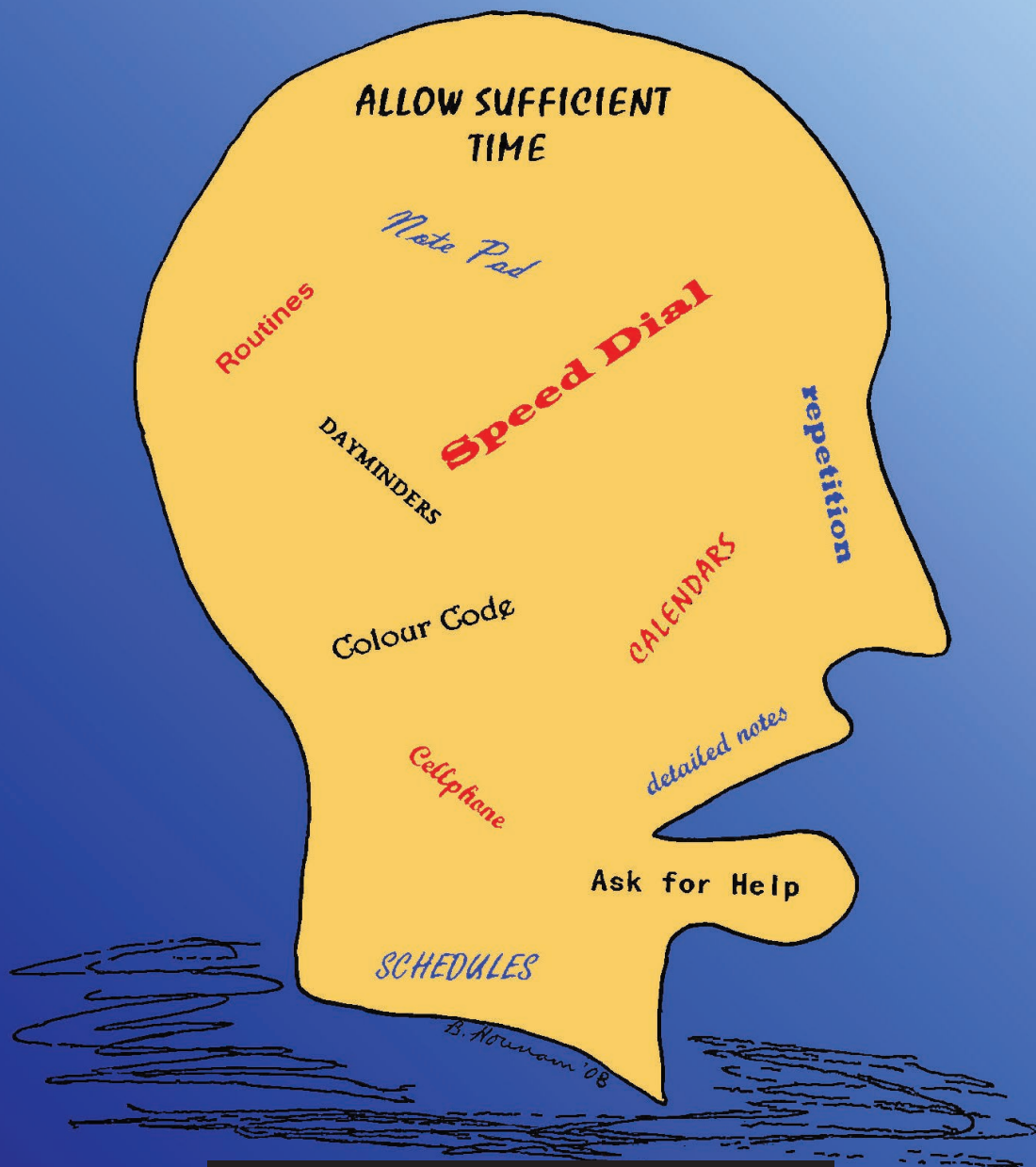




A BY US FOR US GUIDE

Tips and Strategies

An inspirational guide
for people living with dementia

SERIES 1

Introduction

This is the fifth guide in a series of practical and helpful resource guides written by and for persons living with dementia.

Contained in this guide are ideas and suggestions for living daily with dementia. We are all individual and unique in how we live our lives. Because these tips and strategies were provided by individuals living with dementia, they are unique and individual to that person – you need to alter them to fit you and your own life. We recommend that you work with the ideas for a few days and establish a routine that works for you – routines are a very important component of living with dementia. Don't give up on an idea before trying to alter it to fit your lifestyle – one person's idea may trigger ideas of your own – go with it – work through things to create your “new normal”!

Overall, visual aspects of anything we do are important. With dementia you will find that visual cues are even more important now and will become even more so as time goes on. For example, the clothes we wear are often determined by what you first see in your closet – so stacking things too deep in your closet or dresser drawers will not work anymore. Be conscious of this and make the appropriate adjustments.

Allow sufficient time when implementing new routines or incorporating new strategies into your routine. Don't take on too much at once – implement one thing at a time. Prioritize and relinquish things that are not important. If our lives are too cluttered, functioning on a daily basis becomes difficult – like climbing a muddy, slippery slope, you need to find the flat spots. If not, the weight of all the tasks will pull you down the slope.

Introduction continued

Tips and strategies overlap, so strategies come into play in how they work for YOU – don't give up! There is a way to make everything work for us as we live our "new normal".

– Brenda Hounam,
Person living with dementia, Advocate and Spokesperson

This booklet is dedicated in loving memory to my beautiful little granddaughter, **Leah Jennifer Whitney**

Additional memory workouts

As we emphasized in the Memory Workout guide, it is important to continue to use cognitive activities to stimulate the brain. In addition to items listed in the Memory Workout guide, we offer below more suggestions to help you further ‘train your brain’. By devoting an hour each day and at least three to five times per week to these memory workouts, you will notice a change.

Video and computer games

- ✓ Check if you have access to free games on your computer or device (such as FreeCell solitaire).
- ✓ If you are looking at investing in a game system, don't overlook purchasing used equipment and games that are available. Some older computer games are easier to play than the newer ones.
- ✓ Look in the classified section of your local paper or websites that sell used items.
- ✓ Ask your grandchildren to borrow their game systems.

Television game shows

- ✓ Television game shows can provide an opportunity to interact with friends while testing your knowledge.

Additional memory workouts continued

Be creative

- ✓ The advantage of keeping a journal and writing your personal story becomes a great memory resource for yourself and also for your loved ones.
- ✓ Poetry writing is a great way to express all your emotions and can also create lasting memories. For example, Elaine Smith from the Alzheimer Society of Brant and the John Noble Home LEAD Program wrote a poem for her new granddaughter that will be cherished forever.

“Many tears were shed with gratitude that you were finally here. Now, I have my little grandbaby to cherish and love.” (Excerpt written by Elaine Smith entitled, Quinn Ionna Rose)

- ✓ In addition to learning to or playing an instrument, take it a step further and try creating a song or writing the lyrics.
- ✓ Make cooking and baking a more creative process by experimenting with the creation of new dishes
- ✓ Don't be afraid to try new projects, various arts and crafts. Research projects that can be created with minimal tools and for minimal expense, for example, chip carving or Swedish weaving. A great place to explore these options is at craft or woodworking exhibitions.

Additional memory workouts

continued

Keep learning

- ✓ Learning a second language is a good way to stretch your brain.
 - Consider learning the native language of a country you will be visiting on vacation.
 - Learn French before travelling to Quebec.
 - Learn about the languages of the Indigenous peoples living in your community.
- ✓ Don't overlook learning sign language. Your children or grandchildren may also enjoy practicing with you. The important fact is that you keep practicing. One way of doing this is by teaching others, for example, it has become very popular to teach infants and toddlers how to sign.
- ✓ Learn how to use a computer or other device. Have someone take you through the basic steps of using the device and accessing different programs and applications. As you are learning by doing, write or have someone write detailed instructions that you can follow easily at a later date.
- ✓ Learn to type. There are books or computer programs available to help you learn the proper finger positioning. Try typing with both hands and practice these skills by typing letters or emails to family and friends.

Additional memory workouts continued

Keep learning

- ✓ Ask someone to show you how to dictate using a microphone on a device.
- ✓ Use your non-dominant hand to do routine tasks, for example, if you are right-handed, use your left hand to brush your hair or eat your breakfast.
- ✓ Don't underestimate your abilities. Participate in courses, workshops and other learning activities in your community to learn a new skill or activity or learn more information about a topic of interest to you.
- ✓ Learn as much about dementia as you can; as one person living with dementia put it: "Knowledge is power".

Notes

Additional memory workouts

continued

Memorizing

- ✓ Read a magazine, newspaper article or book.
 - Try to recall as much detail as possible.
 - Reading repetitively will help you retain the information, which you may find useful in social situations.
- ✓ Try to remember your daily routine without looking at your to-do list. Or, try to remember at the end of the day everything that you did.
- ✓ Use a collection you have, for example, coins, stamps or spoons, and try to recall the details on how you came in possession of the item – where it came from, and in what year you acquired it. Write those details down to use as a way to reminisce.

Notes

Additional memory workouts continued

Other ideas

- ✓ Getting involved with children can be a great way to train your brain. From playing games, to reading stories and helping with homework. Children can provide cognitive stimulation, socialization and physical activity.
- ✓ Play darts. It can provide mental stimulation and requires you to practice your math skills as well as providing an excellent way to socialize with others.
- ✓ Don't be afraid to try new things.

“I try to keep everything organized. I find my life easier that way. I use a calendar to keep track of my life. I have my husband to drive me and do all shopping with me. I can't do finances; my husband is my power of attorney and I have an accountant.”

(Maureen B., early-stage support group member,
Alzheimer Society of Guelph)

For those in the workforce

In many situations people have noticed memory challenges at work first rather than at home. This can be a blessing because it can initiate a diagnosis and treatment earlier. If you are still working, you need to decide whether to tell your employer about your diagnosis.

Before making this decision, weigh out the situation, on a personal level and on a financial level, and do not let your emotions rule. Rather, turn to someone you trust outside of your situation for advice, for example, a lawyer or financial advisor, and ask a family member or a friend to accompany you when you feel ready to share your diagnosis.

Choosing to tell your employer

- ✓ Some people are fortunate and have a good working relationship with their employers and, therefore, are not fearful of telling them about problems they are experiencing at work. Being proactive in telling your employer about your new situation allows you to remain in control, which can make it easier. Also, confiding in your employer can lead to a discussion on how to accommodate your work duties and schedule to fit your “new normal”.

For those in the workforce continued

Choosing to tell your employer

- ✓ If you are in a financial position, and your employer is agreeable, you may want to reduce your work hours. It is better to make the decision on your own to reduce your work hours than to be forced into it later. However, it is important to seek the advice of a lawyer or financial planner because reducing your work hours may have an impact on your overall benefits and pension especially if you are younger (not such a concern if you are closer to retirement).
- ✓ Your employer may be agreeable to allowing you to job share, or share your role with another employee. The other person can provide support doing more challenging tasks, while you focus on tasks that are more manageable.

Choosing not to tell your employer

- ✓ Some people are not as fortunate and are fearful about telling their employer about their diagnosis. Whether or not you have disclosed your diagnosis to your employer, here are some ways to make your work day more manageable.
- ✓ Avoid multi-tasking. Rather, stick to one task at a time. If that is not possible, limit multi-tasking as much as possible.

For those in the workforce continued

Choosing not to tell your employer

- ✓ Write yourself detailed notes in your day-timer or notebook to remind you not only of appointments, but also the reason for the appointment, who will be attending, where the meeting will take place, and other important information related to the appointment.
- ✓ Be more organized by writing and following a schedule.
- ✓ Learn to say no. Stick to the basics and try not to take on jobs which are beyond your job description.
- ✓ Maintain a good balance between work, social and family life. Get lots of sleep and schedule regular breaks – it is vital now. Watch your diet and avoid heavy meals. Try to exercise regularly.

“I know I’m still doing well because I’m still on the right side of the grass.”

(Jane Mederak, early-stage support group member,
Alzheimer Society of Brant)

General tips and strategies for daily living

Finances

- ✓ Without giving up control of your finances, it is a good idea to have a trusted person who can help with some financial tasks, such as balancing your cheque book and making sure to remind you when a bill needs to be paid. It will be an individual decision however on how much or little control you want over your finances. Make sure to get your legal documentation in place.
- ✓ Use a credit card/debit card rather than carrying large amounts of cash when making a purchase. When you do carry cash, make sure what you carry is in small denominations – nothing larger than a \$20 bill – and try to use the bill closest to the cost of the item. That way, if there is an error in making change the loss of money will be minimized.
- ✓ Set up your finances to include automatic deposits and withdrawals for bill payments.
- ✓ It is important early on in the process to think about and start the process of identifying a financial power of attorney and ensuring all the legal paperwork is completed. This will protect your wishes in the future.

General tips and strategies for daily living continued

Safety and security

- ✓ Register your phone number on a no-call list to minimize the amount of calls from telemarketers. See the Resources section at the back of this guide for the link to make use of this service.
- ✓ Be aware that banks or financial institutions will never request personal or banking information online. **NEVER GIVE OUT YOUR BANK ACCOUNT NUMBER OR BANK CARD PIN NUMBER TO ANYONE REQUESTING THIS VIA EMAIL.** Keep a note about this on your device to remind yourself of this.
- ✓ Be aware of sales people or those looking for donations who come to your door or call you on the phone. Some are reputable; however, some are not. If dealing with anyone who is requesting money or personal information, make sure you have a trusted person by your side. In order to minimize the number of individuals coming to your house, place a “No Soliciting” sign on your front door.
- ✓ Consider getting the call display option on your phone.
- ✓ Minimize the number of keys you carry just in case they are misplaced and do not put your name and address on your keys.

General tips and strategies for daily living continued

Safety and security

- ✓ Try to shop at the same store so that employees can get to know you and you can build a trusting relationship with them. In addition, shop at stores that have a monitor on the cash register where you can see how much each item is, and how much change you are owed.
- ✓ Carry a personal identification card with you in your pocket when you go for a walk or anytime you are not carrying a wallet.
- ✓ Let people know where you are going.
- ✓ Carry a cell phone and use the speed dial option with a list attached to the back of the phone.
- ✓ Register for the Safely Home Program and wear your safely home bracelet at all times. It is an insurance policy and also acts as a form of personal identification. It can also provide your loved ones with peace of mind. See the Resources section at the back of this guide for a link to the Safely Home Program website.
- ✓ When using kitchen appliances or power tools, work cautiously and take it slowly, one step at a time. Consider working on projects with a friend.

General tips and strategies for daily living continued

Safety and security

- ✓ One of the most difficult losses we experience is losing our driver's license. In order to feel a sense of control over the situation, but also to ensure you and others are safe, it is important for you to make the decision to stop driving yourself. This will be a difficult decision. Talk to others about it and determine how you will be supported when you decide not to drive any longer.



For more tips on driving, refer to the By Us For Us guide: **Living Safely**.

Notes

General tips and strategies for daily living continued

Minimize stress

- ✓ Slow down – if you do things too quickly, you may overlook safety, for example, when taking a bath or shower, take it one step at a time – this will give your brain a chance to catch up to your body.
- ✓ Eliminate unnecessary noise and other stimulation – eliminate other distractions in the room, for example, turn off the music or television.
- ✓ If you are involved in a gathering of people, for example, sitting in a restaurant, stay towards the outside of the group, or choose a table in a quieter location such as at the back of the restaurant or beside the wall. That way you will hear noise from one direction only and not from all around you.
- ✓ Give yourself extra time to complete tasks or accomplish activities of daily living.
- ✓ Try to deal with things as quickly as possible, do not worry so much, and try to maintain a calm home environment. Don't forget to take regular breaks.
- ✓ Learn to rest when your body tells you.

General tips and strategies for daily living continued

Visual cues

- ✓ Signage can be written words or pictures. The written word can help to remind you to do things, for example, take your medication or turn off the faucet. Pictures can help label the contents of a dresser drawer or cabinet in the kitchen or workshop.
- ✓ Write detailed notes to yourself.
- ✓ Leave a pad and pen beside the phone in a visible location. Write down phone messages – remind the person on the phone to speak slowly so that you can write the message down.
- ✓ Use a large calendar to remind yourself of appointments and routine tasks, for example, garbage day or adding salt to the water softener. Consider colour coding your calendar – you can use different colours to outline your different appointments or activities, or you can use a different colour for each member of the household.
- ✓ Put pills in a visible location, if appropriate, or use a large visible sign to remind you to take your medication.

General tips and strategies for daily living continued

Visual cues

- ✓ Take pictures of items in the order you like to have them in or of outfits that go together. For example, a person living with dementia completely re-designed her closet by putting clothing items that went together on the same hanger. She made sure she had pictures of all these outfits, which made it easier for putting things away after they were washed.
- ✓ Use post-it notes to keep you on track or remind you what you have to do.

Develop routines

- ✓ Review your daily calendar every morning, and carry with you a pocket day-timer or notebook. Share the content of your day-timer with your care partner.
- ✓ Take your medication consistently at the same time every day.
- ✓ Try to plan to do more difficult tasks when you are the most alert. Put clothes away in your cupboard in complete outfits.

General tips and strategies for daily living continued

Develop routines

- ✓ Put items in consistent locations, for example, place your eye glasses on the night stand before you go to bed or leave your keys in the same location.
- ✓ Wear clothing with pockets so you have a place to put important information, for example, personal identification or a phone.

Entertaining

- ✓ Keep your guest list to a minimum. Tell guests ahead of time when the party starts, but more importantly when it ends.
- ✓ Be well rested and allow time the next day to rest.
- ✓ If you want to entertain around mealtime, order in or arrange a potluck.
- ✓ If you are still cooking, keep the meal simple and the table setting basic.
- ✓ You have to decide what you can or cannot do and do not be pressured into doing more.

General tips and strategies for daily living continued

Electronic aids

- ✓ Use a simple recording device to help you remember significant things.
- ✓ If you have a cell phone, it can be used to stay connected, for example, by getting directions or when you need help while shopping. With a cell phone you can stay connected with someone who can guide you until you reach your destination or you find the item you want to purchase.
- ✓ Use an alarm to remind you of appointments first thing in the morning or to help you know when to take your medications.
- ✓ Timers can be very useful to help remind you of when to change the load of laundry, when you should check something in the oven, or in the workshop.
- ✓ Having a large push button telephone will provide a larger space for writing names on the speed dial list. Having speed dial, call display and voicemail will make using your telephone easier.

“Whatever we are doing, we are doing for ourselves.”

(Carl Wilson, early-stage support group member,
Alzheimer Society of Sarnia-Lambton)

General tips and strategies for daily living continued

General suggestions

- ✓ Keep life simple.
- ✓ Keep your sense of humour.
- ✓ Plan ahead.
- ✓ Communicate your needs to your partner, friends and family, and ask for and accept help.
- ✓ Don't be ashamed – talk openly about what you are experiencing.
- ✓ Check out transportation resources in your own community including organizations that offer volunteer drivers for medical appointments and grocery shopping.
- ✓ Stay engaged, for example, volunteer in your community.
- ✓ Attend a support group.
- ✓ Create a memory box and start writing or record your life story – this is a good way to share with others what is meaningful to you and what you want them to know about you.

General tips and strategies for daily living continued

Notes

“Learning to accept the current situation with its moments of negativity, limitations of memory and minor frustrations that it brings with it. Learning to realize all that has been good in my life, focusing on the good and positive aspects that I have experienced through family, friends.

To appreciate the help that has been provided by the Alzheimer Society – my physician who is currently treating me – my family and friends – this is what is important in managing my daily life.”

(Dr. B. Epstein, early-stage support group member,
Alzheimer Society of Niagara Region)

Let your voice be heard

- ✓ Advocate – speak-up on your own behalf and become a personal advocate, or advocate publicly by speaking with local government officials. People living with dementia are the experts – we need to teach the doctors and professionals about dementia.
- ✓ Don't be afraid to confront other people's misunderstanding about dementia. We can play an important role in teaching others what it is really like to live with dementia and how they can better support us.
- ✓ Offer to go and speak to students training to be doctors, nurses, personal support workers, recreation therapists, and so forth at your local college or university or to speak at community events.
- ✓ Stay active and healthy. Connect with local day programs that provide activities for people living with dementia. This allows care partners time to recharge.
 - For example: the LEAD program (Leisure, Empowerment, Achievement and Dignity), John Noble Home, Brantford, Ontario. This program is run weekly and has transportation to and from the John Noble Home. It offers time for a support session, social activities and a meal offered at the end of the afternoon events. The program structure is decided upon by the group participants and is flexible.

Let your voice be heard continued

- ✓ Try starting a program like this in your area. Approach organizations and churches for assistance, perhaps they can offer a place for you to meet that might even have a kitchen that you can utilize. An occasional social outing or special event is a great start. **Start small and it can build.**
- ✓ Encourage local community organizations to partner with you to develop a learning and sharing forum specifically designed by and for people living with dementia. Visit the Schlegel-UW Research Institute for Aging website (www.the-ria.ca) to learn about A Changing Melody Forum.

“I occasionally enjoy greeting people who are new to our city. The benefits, social skills and introductions open doors and friendships and everyone benefits.”

(Clayton Wilson, early-stage support group member,
Alzheimer Society of Brant)

Brenda's story: The inspiration behind the By Us For Us Guides

When Brenda Hounam was diagnosed with Alzheimer's disease at the age of 53, she realized that very little information was available for people living with dementia. The dominant view was that people living with dementia could no longer learn and be involved in their own care. Brenda knew differently. In 2003, she was inspired to address this gap - to develop a series of resources specifically designed by and for people living with dementia. In 2004, she approached two of her peers with her idea and was surprised by the enthusiasm and support they offered. Through Brenda's contacts at the Alzheimer Society of Brant, the Alzheimer Society of St. Thomas, and the Murray Alzheimer Research and Education Program (MAREP), Brenda connected with various people living with dementia from all around Ontario to work on what came to be called, the By Us For Us (BUFU) guides. These guides provide tips and strategies for managing daily challenges and enhancing well-being for themselves and others living with dementia. Since the publication of the first guide, "Memory Workout", the following guides focused on issues raised by people living with dementia. The project has grown to include three series researched and developed in partnership with people living with dementia and care partners. The philosophy of the By Us For Us guides remains committed, placing importance first on the experiences, suggestions, and tips from those directly affected BY dementia, FOR those directly affected. Brenda has been a true inspiration and role model to her peers. Without her determination and perseverance, this project would not exist or have the international recognition that it does.

Notes

Resources

Alzheimer Society of Canada

Toll-free telephone: 1-800-616-8816

Email: info@alzheimer.ca

Website: www.alzheimer.ca

World Health Organization

Website: www.who.int

Canada's National Do Not Call List

Website: www.LNNT-EDNCL.gc.ca

Medic-Alert Safely Home

Website: www.safelyhome.ca

Also look for arts and crafts ideas online and check for other local, national and international resources.

Endorsements

The “By Us For Us” guides have been enormously helpful to me in my clinic as a Geriatrician. I have used the guides to help individuals and their families master powerful tools that they can draw on to ease the difficulties of living with a dementia. They have been very well received. I am thankful to have the “By Us For Us” guides as a resource.

Sheri-Lynn Kane,
MD FRCPC Geriatrician

Consistent with the previous four “By Us For Us” guides this booklet provides the person living with dementia, their family/ friends, and the health care professional with practical daily living strategies. Sometimes it is hard to know where to begin so a resource such as this is very important. It enables the individual to select and try out strategies to maintain daily function, life roles, and independence.

In the introduction Brenda Hounam validates that change can be difficult, however, ideas, time, and support can lead to a successful “new normal”.

Marion Penko
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The development team

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About the By Us For Us Guides

The By Us For Us Guides (BUFU guides) are designed to provide people living with dementia/care partners the necessary tools to enhance their well-being and manage daily challenges. What makes these guides unique is that they are created BY people living with dementia/care partners, FOR people living with dementia/care partners. The guides include three unique series:

People Living with Dementia: Series 1

This series is written by people living with dementia and covers their experiences. It includes topics such as tips and strategies for managing daily challenges, memory exercises, and enhancing communication and wellness.

Partnership: Series 2

This series is written by both people living with dementia and care partners and covers the partnership experience. It includes topics such as safety, food and mealtimes, social connections, and coping with loss and grief.

Care Partner: Series 3

This series is written by care partners and covers their experiences of supporting a person living with dementia. This series includes topics such as before diagnosis, young care partners, roles, and health and wellbeing.

**To view other guides or order print copies, please visit the Schlegel-UW Research Institute for Aging website:
www.the-ria.ca**

We welcome your input...

If you are living with dementia or are a care partner and would like to comment on this guide, suggest topics for future guides, or participate in future guides, please contact Murray Alzheimer Research and Education Program (MAREP).

Connect with us!

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